

SIBLING CARE IN PEDIATRIC HOSPITALS BY CERTIFIED CHILD LIFE SPECIALISTS

Sibling Care in Pediatric Hospitals by Certified Child Life Specialists

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ABSTRACT

Certified Child Life Specialists (CCLS) assist pediatric patients to promote optimal coping during hospitalization. CCLS provide play, prepare children for medical procedures, and aid in the coping of patients and their families. Recently the field of child life has expanded to include care for siblings of patients, the hospitalization of a sibling is ranked as one of the top stress inducing events for a child. This research specifically aims to uncover the type of care provided to siblings in hospitals by CCLS. While current literature exists regarding sibling needs, there is little information regarding the existence of sibling programs and the interventions CCLS use to help siblings cope. The purpose of this study is to ascertain the psychosocial needs of siblings through a review of current scholarly literature, ascertain the care provided to siblings by CCLS, and uncover gaps in care between what is deemed necessary in the literature and the care that presently takes place in hospitals. To address the latter, I created a survey to assess the current state of sibling programs and interventions used in U.S. and Canadian hospitals. The survey was sent to CCLS across the U.S. and Canada through the use of a national list-serv. The study concluded that there is a high prevalence of sibling programs in medical institutions throughout the United States and Canada. Of the programs represented in the present study, 64% have programs focused specifically on siblings. Focuses of these sibling programs are on education for the siblings as well as on emotional expression for the siblings. Both education and emotional expression were deemed as important by the literature. No real gaps in care for siblings were found. There were, however, areas that the literature deemed important, but were not commonly used by the respondents of the study, including the use of support groups and activities to help children cope with disruption in daily activities. It is the intention of this research that the findings will prompt CCLS nationally to examine their programs to determine

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how to better meet the needs of siblings to positively affect their experience, coping and emotions during a pediatric illness.

INTRODUCTION

Description of the Problem:

In hospitals around the world, Certified Child Life Specialists work with pediatric patients and their families to promote optimal coping during the hospital experience. Child life specialists provide developmentally appropriate opportunities for play, to prepare children for medical procedures, to minimize anxiety in the hospital, to familiarize children with hospital equipment, and to aid in the overall coping of patients and their families (American Academy of Pediatrics, Committee of Hospital Care, 2000). This kind of aid has been provided to hospitalized children from child life specialists since the early 1920's.

Child life specialists embrace the philosophy of family-centered care. Family-centered care is defined as “placing the needs of the child in the context of their family and community, at the center of care and devising individualized and dynamic model of care in collaboration with the child and family” (MacKean, Thurston & Scott 2004, p.75). Therefore, this type of care involves viewing the entire family as the client, and not just the patient. As the field of child life expands, the idea of family-centered care continues to be a central philosophy. This philosophy therefore includes the care of the siblings of the pediatric patient.

The hospitalization of a child presents multiple challenges to the entire family. These challenges arguably cause some of the greatest stress and strain on the siblings of the pediatric patients. Care for siblings of pediatric patients began in the early 1960s (Craft, Wyatt, Sandell, 1985). A body of scholarly work exists detailing the current understanding of the challenges that face siblings of pediatric hospital patients. These siblings face emotional hardships including,

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sadness, fear, loneliness, jealousy, resentment, and guilt (Fleitas, 2000). The siblings of patients also experience confusion regarding the illness of their brother or sister, lack of attention from other family members, and isolation from peers (Fleitas, 2000). These challenges often result in adjustment problems including anxiety, school troubles, and behavior changes (Fleitas, 2000). Child life specialists play a key role in providing therapeutic interventions to these siblings in order to prevent and curtail the issues siblings face.

Because hospitalization focuses primarily on the pediatric patient, there may be less focus on the sibling(s) of the patient. Therefore, an area of research that deserves further expansion is that of the issues facing the siblings of hospitalized children and how Certified Child Life Specialists may best assist these siblings.

This exploratory study has three aims: 1) to ascertain the psychosocial needs of siblings in the hospital through a review of current scholarly literature; 2) to ascertain the care provided to siblings by Certified Child Life Specialists; and 3) to uncover the gap in the care between what is deemed necessary by the literature and the care that presently takes place in hospitals nationwide.

Significance of the project:

The present study holds importance because of the potential positive impact on children, families, and the field of child life. The hospital experience is an extremely stressful experience for siblings. In a study of stressful life events for children, the hospitalization of a brother or sister was ranked as one of the highest stress inducing events for a child (Coddington, 1971). Therefore, the benefits of the study involve finding better ways to assist these siblings and decrease the stress of hospitalization. Through this study, the gaps in care for siblings of hospitalized patients will be uncovered. As these gaps are uncovered, child life programs around

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the nation will be able to examine their own programs to determine how the needs of siblings can be better met. As these needs are better met, siblings of patients will be able to cope more positively with the hospitalization of their sibling. Promoting more positive coping will assist these siblings, as the adverse effects of having a sibling hospitalized can be life-long (Craft, 1995). Also, as siblings of pediatric patients are able to cope more positively, the family as a whole may move into a place of better adjustment; positive changes in one area of a family system typically result in positive changes in other parts (Whitchurch & Constantine 1993); this, in turn, may result in improved interactions with the pediatric patient

KEY TERMS:

Certified Child Life Specialist: Individuals who have met the educational and clinical requirements to be a child life specialist. Certified Child Life Specialists work with pediatric patients and their families to promote optimal coping during the hospital experience. This is accomplished through: providing developmentally appropriate opportunities for play; preparing children for medical procedures; minimizing anxiety in the hospital; familiarizing children with hospital equipment; and aiding in the overall coping of patients and their families

Educational Interventions: The type of intervention in which Certified Child Life Specialists provide developmentally appropriate information to the families of patients regarding the patients' care. These interventions include elements such as teaching the children and parents about the diagnosis and clarifying misconceptions.

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Emotional Expression: The type of intervention in which Certified Child Life Specialists provide opportunities for healthy emotional outlets such as through journaling, talking, or expressing aggression by punching a pillow.

Medical Play: Any play with the use of real or play medical equipment, including both adult-directed and child-directed play. This play can range from dramatic play with the medical equipment to art projects with the equipment.

REVIEW OF SCHOLARLY LITERATURE

A body of research currently exists which examines the areas of need for siblings of pediatric hospital patients. The themes within the research regard the topics of: common emotions and issues experienced by siblings; parental influence on siblings; a need for education of siblings; and finally possible interventions for siblings.

Theoretical Framework

This topic will be examined through the lens of the family systems perspective. The family systems perspective defines the family as “a complex structure comprised of an interdependent group of individuals who have a shared sense of history, experience some degree of emotional bonding; and devise strategies for meeting the needs of the individual family members and the group as a whole” (Anderson & Sabatelli, 2011 p. 6).

The family systems perspective demonstrates that the diagnosis of an illness impacts the entire family system. One adaptation made in families following the diagnosis of a chronic illness involves structural changes. As Georganda (1985) suggests, when a pediatric illness is diagnosed, the largest structural change takes place as a coalition is formed between the

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caretaker parent and the ill child. This coalition is usually led by the mother who takes on a large caretaking role in the maintenance and care of the sick child. (Georganda, 1985). This research also found that families tend to reorganize boundaries based on a chronic illness diagnosis. It was stated that there is a “tendency to isolate from the rest of the surrounding world ” (Georganda, 1985). Also, internal boundaries within the family may shift. Older siblings may become a part of the parental subsystem as they assist in the care of the sick sibling. Also, the sick child may take a different role in the family as he or she acquires a central position of importance in the family (Georganda, 1985). Also it was found that along with these structural changes, family norms and rules change following the diagnosis in order to fit the needs of the sick child such as adjustment in behavior rules for the ill child. It was also found that internally, many individuals may become more rigid as they foster feeling of guilt, anxiety and anger, but are unable to express these feelings (Georganda, 1985).

The family systems perspective also emphasizes the importance of interdependence within the family. This interdependence is evident as factors that impact one family member tend to impact the rest of the family system (Anderson & Sabatelli, 2011). Therefore, while the hospitalization of a child may appear to only impact the patient, the siblings and the rest of the family are affected; for example, as indicated, the siblings may experience a stress response which manifests in emotional and behavioral problems. This understanding of the impact on the family system demonstrates the need for child life specialists to provide care to families during hospitalization as the child life specialist can help intervene to assist in more positive outcomes for children and families. This also indicates that siblings are greatly affected by the diagnosis of illness in their sibling and therefore will benefit greatly from interventions by child life specialists.

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Common Emotions and Issues Experienced by Siblings

The current scholarly literature points to many common emotional and behavioral challenges that face siblings as they experience the hospitalization of their brother or sister. Newton, Woglemuth, Gallivan, and Wrightson (2010) conducted a survey to 107 children's hospitals in the United States and Canada. Through this study it was found that, "significant restructuring of family routines and focus occurs" when a child is hospitalized, which therefore points to a need for sibling programs as the child life specialist can utilize the program and its resources to help siblings cope with this restructuring. This restructuring takes the form of alterations in the sibling's typical routine including: separation from their parents; feelings of confusion about changes in the family; and may result in loss of appetite; inability to sleep; challenges in concentration; difficulty in school; and fear for their own health (Newton, et. al., 2010).

In a study conducted by Craft, Wyatt, and Sandell (1985), 123 siblings of pediatric patients and their parents were interviewed using face-to-face interviews and questionnaires regarding behavioral and emotional changes as a result of the ill child's hospitalization. On average, the children reported experiencing four changes. These changes were noted to vary based on the age of the sibling, the sibling's relationship with the ill child, the sibling's understanding of the medical experience, and the sibling's fear of contracting the illness (Craft, et. al., 1985). Younger siblings were found to be fearful of contracting the illness, and to feel guilty or responsible for the illness. These feelings manifested in school problems, depression, or illness in the sibling (Craft, et. al., 1985, p. 374). Younger siblings were also found to have greater alterations in behavior and feelings than their older peers. Children whose siblings had progressive illnesses, showed the most behavioral and emotional changes. Siblings of patients

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with acute illnesses, such as appendicitis, were reported to experience the least amount of behavioral and emotional changes in comparison to other types of illnesses. Length of illness was also correlated with changes as longer illnesses lead to more behavior and feeling changes. Overall, Craft et. al. (1985) found that among siblings of pediatric patients the most common feeling was a desire to spend more time with their parents, followed by reports of a decreased amount of food eaten, increased nerves, and challenges in concentration (Craft, et. al., 1985).

Fleitas (2000) collected sibling responses regarding their emotions following a sibling's hospitalization from interviews as well as comments on the sibling support website "Band-Aides and Blackboards: When Chronic Illness...or Some Other Medical Problem...Goes to School." Common themes arose from these siblings including: feeling responsible for the illness; being fearful; being jealous and resentful of their sibling; feeling embarrassed and sad; and feeling confused (Fleitas, 2000) Siblings were also found to be at an increased risk for low self-esteem as well as trouble with peer-relationships (Fleitas, 2000). Some positive changes were also found, including growth in skills such as resilience and empathy.

Bendor (1990) conducted two age-related discussion groups of siblings of ill children and found that the younger children experienced common feelings of "deprivation, displacement, injustice, anger, loneliness and vulnerability" (Bendor 1990, p. 24). The adolescent group reported fears of death, a sense of responsibility for their sibling's well-being, concerns over pursuing their own lives while their sibling was sick, and conflict on the type of information to withhold from others regarding the illness (Bendor, 1990). Adolescents also expressed fears of getting an infection, such as the common cold, that could be a cause for killing their sibling.

Menke (1987) interviewed 72 siblings of children with chronic illness. In that study, 68% of those interviewed expressed worry about their ill sibling. Also, 49% of the children expressed

“protective concerns” of their ill sibling, meaning they felt that they needed to be protective of the ill sibling (Menke 1987, p. 135). Protective concerns were more common in the siblings who were older than the ill sibling.

For children and adolescents who experience the loss of a sibling, many similar emotions are experienced. Along with the previously stated common emotions, siblings of deceased children who struggled with an illness may experience: shock; disbelief; guilt; anger; numbness; and fear. Over time these feelings tend to decrease, along with the more complicated symptoms of grief such as inability to sleep and hallucinations (Walker 1993)

Parental Influence

Along with the challenges faced in hospitalization, many issues also arise for siblings tied to their parents. Siblings face stress and anxiety as they are often separated from their parents during hospitalization (Newton, et. al., 2007). Siblings also face an increase in behavioral changes when they feel that their parents are spending an inadequate amount of time with them, or that their parents are focusing their time only with the ill child (Craft et. al., 1985). It was also notable that the children in the study conducted by Craft et. al (1985) reported greater changes in themselves than their parents reported in them, such as commonly reporting a desire to spend more time with their parents. Menke (1987) explained the need to consult siblings regarding their perceptions and emotions regarding the ill sibling because it was found that parents reported different concerns than their children reported (Menke, 1987).

One of the most stressful aspects of hospitalization were siblings’ perceptions of changes in their parents’ supervision, emotional availability and anger (Craft 1993). Bendor (1990) found that well-siblings require attention from their parents, even during times of high stress with the ill child (Bendor, 1990). Bendor also found that children reported unfair parenting as the ill child

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was allotted different behavior rules than their healthy siblings, which caused the other children to feel devalued and not as important as the ill sibling (Bendor, 1990).

Kaplan, Grobstein, and Smith (1976) conducted a prospective study of 40 children with leukemia and their families. The families were followed from the time of the diagnosis of the ill child until several months after the child passed away. This study found that children whose parents were not honest with the siblings regarding the seriousness of the leukemia while the child was still alive increased the likelihood of issues between the parents and the sibling following the child's death (Kaplan, et. al., 1976). These issues were attributed to mistrust of the parents following the lack of information regarding the ill child.

Significant restructuring of familial roles and routines occur during hospitalization, which increases stress in siblings (Craft, 1993). Bendor (1990) explains that advocating for family centered care is crucial for the most optimal coping to occur in siblings. This is important as all within the family are affected by hospitalization, and working with the family as a whole can alleviate some stresses.

For siblings of deceased patients, the relationship with parents was also found to be complicated by the loss. Siblings who scored low in tests of self-concept were found to have a feeling that they could not meet the expectations of their parents following the death, and that the deceased child was favored in the family. For children who tested high in self-concept stated that they felt their parents were proud of them for becoming stronger after the experience of loss (Walker 1993).

Need for Education

Craft et. al. (1985), found that siblings who were provided with little or no explanation regarding hospitalization faced the largest amount of adverse behavior changes. This was

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potentially due to the fact that a vague explanation may produce anxiety in siblings. Therefore, open explanations of the hospitalization were found to have the most positive outcome for siblings (Craft, et. al., 1985).

Educational interventions were also found to be crucial in a study conducted by Gursky (2007). Gursky (2007) conducted a study on 50 siblings of hospitalized patients. The participants were between the ages of six and seventeen. The experimental group, which consisted of 25 children, received educational interventions from child life specialists within the hospital. The interventions were designed based on using developmentally-appropriate activities to describe: hospitalization; medical procedures; the treatments their siblings were receiving; and information regarding the illness or injury. The control group was not given these interventions. Both groups received pre and post-tests regarding their anxiety level. Those siblings who received the intervention had decreased anxiety compared to those who did not receive the intervention (Gursky, 2007). Both groups of siblings, however, did have anxiety levels above the normal level. Craft (1993) also noted that it is crucial for younger children that educational interventions include concrete explanations of the hospitalization as younger children have trouble with abstract thinking as it is separate from experience (Craft, 1996). Sibling visitation was also found to be of great important as it is unlike any other method of explaining the circumstances of the ill child to siblings as they can “see, feel and touch the ill child, as well as observe what the ill child is experiencing” (Craft 1993, p. 295). This visitation is especially important for younger children who think concretely and cannot abstractly understand what is occurring in the hospital without witnessing it (Craft, 1993).

Similarly, education was found to be important for bereaved siblings. Siblings of dying patients who received education and support prior to the death, demonstrated a more positive

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recollection of the death including more parental support and more knowledge of the impending death (Walker 1993)

Interventions

It was noted by Craft (1993) that the most successful interventions for siblings focus on “stress reduction” and the “facilitation of coping” (Craft 1993, p. 291). Newton, et. al. (2010) found that 48% of pediatric hospitals in the United States and in Canada offered sibling support intervention programs. The programs mainly involved grief assistance, therapeutic play, and basic entertainment, such as video and computer games. Only one-fifth of the programs surveyed provided educational resources (Newton, et. al., 2010). Child-care was offered for siblings in 12% of the respondents’ hospitals. When funding was available for programs, more expansive intervention programs were possible for sibling support (Newton, et. al., 2010). The study concluded that many hospitals do not provide sibling support, but the hospitals surveyed recognized the importance to develop an assessment and evaluation tool for siblings.

The current scholarly literature noted the importance of using support groups to assist siblings. Fleitas (2000) stated that there are rare opportunities for siblings to speak with peers in similar circumstances. Fleitas (2000) concluded that support groups that could bring children together facing similar issues would be of great benefit to siblings. Another important intervention found by Fleitas (2000), was to allow for the siblings to openly express their emotions regarding hospitalization.

METHODS

From the gaps identified in my systematic review of the literature, I designed a survey to comprehensively assess the types of programs currently offered in U.S. and Canadian hospitals

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for sibling support during a pediatric patient's illness. The experts who assisted included a Certified Child Life Specialist, and two individuals well-published in the field of Human Development and Family Science: Dr. Anastasia Snyder and Dr. Amy Bonomi.

The survey was administered to individuals via the national list-serv of child life specialists through the Child Life Council. The Child Life Council develops the standards for obtaining professional credentials and provides opportunities for professional dialogue and discussion on its national discussion forum. The Child Life Council is a non-profit organization, which promotes "quality child life services in health care environments" (Child Life Council). An introductory letter about the study and a link to the online survey were sent to Certified Child Life Specialists through the Child Life Council's list-serv. At two and four weeks, follow-up reminder emails were sent through the forum. The survey included an introduction detailing the purpose of the survey as well as a consent form. The survey was sent to approximately 4,000 individuals via the list-serv. Not all who received the survey were eligible for the study, but it was not possible to eliminate ineligible participants at the start of the study. The survey method was still used, as it was the best mechanism to reach those potentially eligible for the study.

However, in the analysis phase, data were not used from respondents who were not certified as a child life specialist, and those who were not employed. Only one respondent per medical institution was used, thus if two respondents from the same medical institution responded only one response was used. This study is a convenience sample that is intended to be exploratory.

RESULTS

Demographics of Respondents

Of those who responded to the survey (n=74) , 76% (n=56) were eligible because they were employed Certified Child Life Specialists who represented a unique medical institution. The 76% comprised our analytic sample.

In keeping with the study criteria, all respondents were Certified Child Life Specialists and employed as such in a medical institution. Characteristics of the sample included: 100% of the sample was female and age ranging from 24 to 60 years old (average age, 32.9 years). The highest level of degree attainment of the respondents was nearly split as 52% reported earning Bachelor's degrees and 48% reported earning Master's degree or above. The large majority of the sample was employed in the hospital setting (94.6%), however few respondents indicated employment at other medical institutions (5.4%) (such as a palliative care center). Respondents who work in hospitals ranged from employment in free-standing children's hospitals to employment in children's hospitals within adult hospitals. Respondents were from throughout the United States and Canada including responses ranging from Texas to California and from Florida to New Jersey.

Existence and Type of Sibling Program

The existence of sibling programming in the medical institutions in the sample was found to be quite high. Of the respondents surveyed, 64% indicated the existence of sibling programs in their medical institution. The respondents showed the programs have a strong emphasis on the education of siblings regarding the health care experience. As the respondents are all Certified Child Life Specialists, they understood education to mean providing developmentally appropriate information to the families of patients regarding the patients' care. This includes

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elements such as teaching the sibling and parents about the diagnosis and clarifying misconceptions. The educational components include: education for siblings in 86% of the medical institutions in which the respondents work; education for parents in 79% of the medical institutions in which the respondents work; and informational materials, such as hand-outs, in 74% of the medical institutions in which the respondents work.

Other services provided by the medical institutions included: a play space within their medical institution for siblings (57%); activities geared specifically toward siblings (57%); and evaluation and assessment of siblings of patients (57%). As child life specialists, the respondents understood evaluation and assessment to include learning about the medical aspects of the patient, the sibling's developmental level, assessing environmental stressors for the sibling, and evaluating other relevant information related to how the sibling will cope with the medical experience. Other programs in the medical institutions include: support groups for siblings (38%) and day-camps for siblings of patients (12%).

Finally, 29% of the respondents said other types of sibling programs not included in the survey were sometimes used. Examples of these other types of programs include: providing schooling to siblings and the celebration of sibling month. The respondents also indicated the use of outside programs such as: "Sibshop" (an international program for siblings of ill and disabled children to engage in activities together), and "Sibling Beads of Courage," (siblings earn decorative beads throughout the challenges they face during the patient's hospitalization). Additional information regarding these programs can be found in the reference page.

Interactions with Siblings

I had two questions about interactions with siblings in the survey. The first question requested information about how often during the past 6 months the Certified Child Life

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Specialists interacted with siblings of patients. In terms of actual interaction patterns, 28% of the respondents stated interacting with siblings weekly, 28% interacted with siblings 2-4 times per week, 26% of the respondents interacted on a daily basis, and 22% interacted 1-2 times per month.

The second question asked the respondents which types of interventions were used during their interactions with siblings. The majority of interventions used by the Certified Child Life Specialists surveyed involved education for the siblings (as described previously) and normalization play, which includes typical play for the sibling away from the medical environment. Both education and normalization play were used by 84% of Certified Child Life Specialists surveyed. Similarly, 63% of Certified Child Life Specialists engaged in activities of emotional expression with the siblings. Medical play was used by 32% of the respondents such as creating art projects with medical items and playing through a medical experience using a doll and medical equipment. Distraction during procedures or other stressful events was used by 18% of the respondents. Another 13% of the respondents stated the use of other types of interventions than those stated in the survey. These other interventions include: helping the sibling debrief after experiencing a trauma, preparing the sibling to visit the patient inside an Intensive Care Unit, and legacy building activities for the sibling following the death of the patient including creating handprints and other memorable items for the family.

Prioritization of Sibling Needs

Child life specialists work with large groups of patients. As the child life specialists may not be able to visit each patient and family every day, prioritization of needs becomes important. Thus, in order to ascertain how this prioritization translates into the needs of siblings, the researcher asked the respondents to prioritize/rank several needs of siblings. The average ranking

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from the respondents from highest priority need to lowest priority need was: the needs of bereaved siblings; the needs of siblings of chronically ill patients; the needs of the siblings to cope with their feelings; the needs of siblings of acutely ill patients; the needs of children based on their age; and finally the challenges faced during the disruption in daily activities.

Along with the prioritization of needs, respondents were asked to rank factors concerning the sibling's ability to cope. The rankings, from highest concern to lowest concern, were: grief and bereavement; age appropriate explanations of the disease and hospitalization; the sibling's emotional responses hospitalization; daily disruptions due hospitalization; length of the sibling's hospitalization; and finally time with children facing similar experiences.

DISCUSSION AND CONCLUSION

As the purpose of this exploratory study was to determine the gaps in care between the care deemed necessary by the literature and care that currently takes place in medical institutions, the above data will be compared to the previously found needs.

Comparison of Existing Research to Findings from the Present Study

The literature indicates several challenging emotions experienced by siblings during illness or hospitalization of their brother or sister such as jealousy, anger, and anxiety. The respondents in my survey likewise indicated a large emphasis on assisting siblings and their families cope with challenging emotions during the hospitalization of the patient—ranking it as the third most pressing concern for siblings. Survey respondents also indicated the use of emotional expression interventions including encouraging healthy emotional expression through journaling or art projects, as occurring often. Emotional expression was indicated as used by 63% of the respondents

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Survey respondents accurately assessed and prioritized the needs of siblings as was indicated by the literature. Siblings of acute patients were found by Craft et.al (1985) to experience the least amount of behavioral changes due to the illness. This was reflected in the results as the respondents indicated a lower priority need for siblings of acute patients, whereas longer illnesses (more chronic illness) were shown to cause more behavioral changes. The respondents indicated that this need is higher than the needs of siblings of acutely ill patients by ranking the priority of needs of siblings of chronic patients higher than the needs of siblings of acutely ill patients.

As noted from the literature, parents play a large role in how siblings cope with hospitalization. Siblings indicated that unfair treatment from their parents as well as inadequate information from their parents causes high levels of stress. The Certified Child Life Specialists surveyed demonstrated their emphasis on quelling these stressors as education for parents regarding siblings was noted to occur from 79% of the respondents.

Education was deemed of utmost importance in the literature. Craft et. al (1993) found that siblings who received age-appropriate education about hospitalization demonstrated the least amount of adverse behavioral changes due to hospitalization. Similarly, a study by Gursky (2007) found that those children who received developmentally appropriate information from a child life specialist had a reduction in anxiety in comparison to children who received no treatment. Education for bereaved siblings is also important in preventing adverse reactions. The respondents to the study showed the high importance of education for siblings as 86% of the respondents indicated education for siblings as a part of the sibling program in their medical institution. This was a large increase in educational interventions from a previous study

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conducted by Newton, et. al. (2007), as only less than one-fifth of respondents in Newton's study indicated educational programs.

Along with the higher existence of sibling programs for education, 84% of respondents indicated using educational interventions in their personal interactions with siblings. Similarly, age-appropriate explanations of the disease and hospitalization were ranked as the second highest priority in sibling care, only following grief and bereavement support. The research also indicated that many fears for siblings are associated with contracting the illness, or feeling guilty or responsible. Thus the educational interventions assist in clarifying these misconceptions. Medical play, which is often used to assist children in understanding and dispelling misconceptions about hospitalization was also used by 55% of the respondents.

Gaps in Care

Throughout this research there were virtually no real gaps in care found, rather there were areas that were deemed important in the literature that were found to occur less often or be ranked as a lower priority than other needs. Fleitas (2000) found that support groups are very important for the coping of siblings. However, the present study found that only 38% of respondents indicated the use of support groups in their medical institution. Similarly, "time spent with children facing similar experiences" was rated as the least concern in a list of concerns facing siblings. This smaller number of support groups may be attributed to limited funding and staffing necessary to hold support groups. The lower ranking of time spent with children facing similar experiences may be attributed to the fact that many high stress factors were listed and this factor was simply put last as the lesser of the evils. The present literature also demonstrated that disruption in the daily life of the siblings is a significant stressor to the siblings. However, the respondents ranked "disruption in daily activities" as the lowest priority

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in a list of needs of siblings. Again, this may be attributed to the fact that this was seen as a lesser of the several evils including the needs of bereaved siblings. Age was also correlated with behavior changes, as younger children had more behavior changes in Craft's study (1985). However, the respondents in this study ranked the age of the sibling as a lower priority when prioritizing the needs of siblings of patients.

Conclusion

In conclusion, the present study found that many medical institutions have sibling programs. Virtually all respondents indicated the use of some sibling support and 64% of the respondents indicated the existence of a sibling specific program in their medical institution. Even Certified Child Life Specialists working in medical institutions without sibling specific programs interacted with siblings at least monthly.

The needs of siblings seemed to be regularly and adequately addressed by respondents within their medical institutions. The needs addressed include opportunities for emotional expression and education. However, respondents indicated some areas for improvement, including the use of support groups, the use of activities geared toward helping siblings handle the disruption in daily activities, and the prioritization of siblings based on age.

There are some limitations to consider from the present study. To begin, the data were analyzed from responses from the sibling programs in 56 medical institutions. This is a relatively small sample and may compromise generalizability. Another limitation is that the question "Where do you work?" was misread by some respondents. Rather than responding with the name of their medical institution, several respondents gave more general responses such as by stating "Pediatric Hospital." If this study were to be replicated, this question could be reworded to ascertain more clear results. There may also be a selection bias in this study. Only those who

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desired to do so answered the survey. Therefore, this may only include the respondents who: felt that they had something valuable to share and those who had the time to respond. This may mean that those who responded had an interest or investment in sibling care, or those who responded work in a setting where they have the time to respond (this may eliminate smaller or one-person programs). Areas for future research could include the effectiveness of the sibling programs, and research regarding the implementation of new sibling programs.

These limitations notwithstanding, the present study shows the importance of the needs of siblings of hospitalized patients. It is concluded that these needs are well addressed by Certified Child Life Specialists such as through providing the siblings with appropriate education and with opportunities to express their emotions. These programs can be improved by providing support groups for the siblings and intervening for siblings regarding the stressors of their daily disruptions due to hospitalization. Over the long run, with these changes and the addition of further sibling programs, it is anticipated that more positive outcomes for the siblings of pediatric patients can be created.

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APPENDIX A: Survey Questions

1. Are you a Certified Child Life Specialist? Yes No

2. Are you currently employed as a CCLS? Yes No

3. Gender: Male Female

4. Age:

5. What is your highest educational degree attained?

Bachelor's Degree

Master's Degree or above

6. Where do you work?

7. Does your place of work have a sibling support program?

Yes No

If yes, what type of sibling program(s) does your place of work have? (check all that apply)

- None
- Support groups
- Education for siblings
- Education for parents
- Evaluation/assessment of siblings
- Play space
- Activities geared specifically toward siblings
- Day camps
- Hand-outs (or other informative materials)
- Other
 - o Please explain
- None

8. In the last 6 months on average how often did you interact with siblings of patients per month?

Never

1-2 times per month

Weekly

2-4 days per week

Daily

9. During interactions with siblings what interventions did you use? (please check all that apply)

- Medical Play:

How effective was this intervention, on a scale of 1-5 (1 not at all effective, 5 very effective)

1 2 3 4 5

- Distraction

How effective was this intervention, on a scale of 1-5 (1 not at all effective, 5 very effective)

1 2 3 4 5

- Emotional expression

How effective was this intervention, on a scale of 1-5 (1 not at all effective, 5 very effective)

1 2 3 4 5

- Education

How effective was this intervention, on a scale of 1-5 (1 not at all effective, 5 very effective)

1 2 3 4 5

- Normalization play

How effective was this intervention, on a scale of 1-5 (1 not at all effective, 5 very effective)

1 2 3 4 5

- Other

Please describe:

How effective was this intervention, on a scale of 1-5 (1 not at all effective, 5 very effective)

1 2 3 4 5

10. How do you prioritize the needs of siblings? Please place the below in order (Mark your top priority as 1 to lowest priority as 6):

- _____ Disruption in daily activities
- _____ Age
- _____ Coping with feelings
- _____ Siblings of chronically ill patients
- _____ Siblings of acute patients
- _____ Bereavement support

11. Which of the following do you feel are of the utmost concern regarding siblings? Please rank the following (Mark 1 as the highest concern to 6 as the least concern)

- _____ Age-appropriate explanations of disease/hospitalization
- _____ Emotional responses to hospitalization
- _____ Daily disruptions due to hospitalization
- _____ Grief/bereavement
- _____ Time with children facing similar experiences
- _____ Length of sibling's hospitalization

APPENDIX B: Recruitment Letters

Dear members of the Child Life Council,

I am an Undergraduate student in the Department of Human Development and Family Science at The Ohio State University. I would like to invite you to participate in my research study to ascertain the care provided to siblings of hospitalized patients by Certified Child Life Specialists. This study is entitled Sibling Care in Pediatric Hospitals by Certified Child Life Specialists. You may participate (*or may not participate*) if you are an employed Certified Child Life Specialist.

Participants will be asked to complete a brief online survey that will take approximately 20 minutes.

This study involves very minor risks that may include stress or minor feelings of job inadequacy. Benefits include finding gaps in care of siblings within the hospital so that the gaps may be filled, which will increase coping for siblings of pediatric patients within the hospital. Your response will be kept confidential. Please note, we will work to make sure that no one sees your survey responses without approval. But, because we are using the Internet, there is a chance that someone could access your online responses without permission. In some cases, this information could be used to identify you.

If you would like to participate in this study, a consent form and the survey can be obtained by clicking on this link https://eheosu.qualtrics.com/SE/?SID=SV_77cR0AltcpuKGKF

If you have any questions, please contact me at Schwartz.1663@buckeyemail.osu.edu or my advisor, Dr. Eugene Folden at folden.1@osu.edu

Thank you for your consideration,
Lindsay Schwartz

Follow up email 1:

Dear members of the Child Life Council,

This email serves as a reminder of the opportunity to complete a brief online survey regarding sibling care in your hospital. I am an Undergraduate student in the Department of Human Development and Family Science at The Ohio State University. I would like to invite you to participate in my research study to ascertain the care provided to siblings of hospitalized patients by Certified Child Life Specialists. This study is entitled Sibling Care in Pediatric Hospitals by Certified Child Life Specialists. You may participate (*or may not participate*) if you are an employed Certified Child Life Specialist.

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Participants will be asked to complete a brief online survey that will take approximately 20 minutes.

This study involves very minor risks that may include stress or minor feelings of job inadequacy. Benefits include finding gaps in care of siblings within the hospital so that the gaps may be filled, which will increase coping for siblings of pediatric patients within the hospital. Your response will be kept confidential. Please note, we will work to make sure that no one sees your survey responses without approval. But, because we are using the Internet, there is a chance that someone could access your online responses without permission. In some cases, this information could be used to identify you.

If you would like to participate in this study, a consent form and the survey can be obtained by clicking on this link https://eheosu.qualtrics.com/SE/?SID=SV_77cR0AltXpuKGKF

If you have any questions, please contact me at Schwartz.1663@buckeyemail.osu.edu or my advisor, Dr. Eugene Folden at folden.1@osu.edu

Thank you for your consideration,
Lindsay Schwartz

Follow up email 2:

Dear members of the Child Life Council,

This email serves as the third and final reminder of the opportunity to complete a brief online survey regarding sibling care in your hospital. I am an Undergraduate student in the Department of Human Development and Family Science at The Ohio State University. I would like to invite you to participate in my research study to ascertain the care provided to siblings of hospitalized patients by Certified Child Life Specialists. This study is entitled Sibling Care in Pediatric Hospitals by Certified Child Life Specialists. You may participate (*or may not participate*) if you are an employed Certified Child Life Specialist.

Participants will be asked to complete a brief online survey that will take approximately 20 minutes.

This study involves very minor risks that may include stress or minor feelings of job inadequacy. Benefits include finding gaps in care of siblings within the hospital so that the gaps may be filled, which will increase coping for siblings of pediatric patients within the hospital. Your response will be kept confidential. Please note, we will work to make sure that no one sees your survey

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If you would like to participate in this study, a consent form and the survey can be obtained by clicking on this link https://eheosu.qualtrics.com/SE/?SID=SV_77cR0AltcpuKGKF

If you have any questions, please contact me at Schwartz.1663@buckeyemail.osu.edu or my advisor, Dr. Eugene Folden at folden.1@osu.edu

Thank you for your consideration,
Lindsay Schwartz